

# Advance Directive vs. Oregon Law

Updated

ISSUES, CONCERNS AND A PROPOSAL

~~May 11, 2017~~

~~December 1, 2017~~

**February 6, 2018**

William L. Harris

# Why are we meeting?

- The Advance Directive by Oregon statute does not deal with the issue of dementia, and as you will see later, it specifically prohibits this issue.
- Nora was unable to utilize the lawful assisted suicide mechanism because it specifically requires the person to be of rational, sound mind at the time of obtaining the drugs and their use.
  - Nora was not of rational or sound mind at that time this would have normally been used.
- The organizations and people (Memory Care Facilities, Hospice and the medical staff) who take care of people with dementia are not operating in a culture that is conducive to meeting the wishes of such patients. They were:
  - Hesitant of providing comfort at time of death (morphine and anti-anxiety medicine)
  - Still trying to feed her when she could not swallow six days before her death, and the
  - Doctor would not write an order to not feed until 36 to 48 hours before her death.
- I am in favor of HB 4135 which establishes an Advance Directive Adoption Committee for purpose of adopting form of advance directive to be used in this state, as a first step.
  - As an aside, I would like to be on this committee to represent people who are care-givers of people with dementia.

# Evidence of Not Understanding Dementia or Alzheimer's Disease

- Bruce Van Zee, MD requested a rule change:
  - “After a delay of 5 months, this is the official response to our request to alter the administrative rule for LTC facilities to allow a specific exception to assisted/spoon feeding if so requested by an addendum to a person's AD....” (1)
- Here is the essence of the response:
  - This email is in response to your request for clarification from the Department of Human Services (hereinafter Department) regarding whether the Department could require a facility to honor a request made by someone who does not want spoon or assistance eating if they are unable to do so on their own. An Advance Directive for Health Care is governed by statute. Oregon Revised Statute (ORS) 127.505 defines “advance directive,” “artificially administered nutrition and hydration” and “health care” as:
    - (2) “Advance directive” means a document that contains a health care instruction or a power of attorney for health care.
    - (4) “Artificially administered nutrition and hydration” means a medical intervention to provide food and water by tube, mechanical device or other medically assisted method. “Artificially administered nutrition and hydration” does not include the usual and typical provision of nutrition and hydration, such as the provision of nutrition and hydration by cup, hand, bottle, drinking straw or eating utensil. [emphasis added]
    - (8) “Health care” means diagnosis, treatment or care of disease, injury and congenital or degenerative conditions, including the use, maintenance, withdrawal or withholding of life-sustaining procedures and the use, maintenance, withdrawal or withholding of artificially administered nutrition and hydration.

(1)[From: Bruce Van Zee [\[mailto:bvz@charter.net\]](mailto:bvz@charter.net); Sent: Friday, May 05, 2017 4:44 PM; To: Goldberg, Adrienne; Bill Harris; Joanne Kliejunas; [efoster@fosterdenman.com](mailto:efoster@fosterdenman.com); Gell, Jonathan; Grebosky, James; John & Lynn Forsyth; Angela Warren; Subject: Fwd: Spoon or Assisted Feeding

# Evidence of Not Understanding Dementia or Alzheimer's Disease

- *An Advance Directive for Health Care, by statute can only include directions on health care, which by definition, only includes artificially administered nutrition and hydration. Therefore, an Advance Directive for Health Care in Oregon cannot include "special instructions that fall outside the definition of health care. Just to emphasize this, ORS 127.642 restates the items that should be offered regardless of the withdrawal of artificially administered nutrition and hydration, and includes "reasonable efforts to offer food and fluids orally."* [emphasis added]
- Pursuant to the above information, the Department is not able to change our administrative rules. ***A statutory change would need to occur first in order for the Department to explore a change.*** [emphasis added](2)
- Last year's Advance Directive SB494 and this year's bill HB 4135 (Establishes Advance Directive Adoption Committee for purpose of adopting form of advance directive to be used in this state) do not address this issue or these definitions.
  - The workshop I attended on last year's bill before it was considered to be a bill, purposely put into abeyance the issues of Voluntary Stopping Eating and Drinking (VSED); spoon or assisted feeding; and
  - Did not address the statute which allows for ignoring this language ("no assisted feeding") in your Advance Directive.

(2) From: Potter Ana M [ANA.M.POTTER@dhsosha.state.or.us](mailto:ANA.M.POTTER@dhsosha.state.or.us); Date: May 5, 2017 at 4:27:32 PM PDT; To: Bruce Van Zee [bvz@charter.net](mailto:bvz@charter.net); Cc: Mcqueen Ann E [ANN.E.MCQUEEN@dhsosha.state.or.us](mailto:ANN.E.MCQUEEN@dhsosha.state.or.us); Subject: Spoon or Assisted Feeding

# Future Proposal

- This clarification and referenced statutes are a fundamental challenge to the idea and efficacy of the Advance Directive.
  - An Advance Directive is to provide a mechanism for the person to state their wishes/desires on how to end life when they cannot speak for themselves.
  - The state takes the position that the Advance Directive is only for the decision on artificially administered nutrition and hydration and "...cannot include special instructions that fall **outside** [emphasis added] the definition of health care...."
- I am proposing that one of two things happen with the new Advance Directive that is being considered by the legislature:
  - 1) Either there be a separate section of the Advance Directive that is specifically designed for persons who have been formally diagnosed with dementia or Alzheimer's Disease.
    - This section would specifically deal with "assisted feeding" in addition to other specific issues.
    - If the person selected "no assisted feeding"; then this would not be overridden by statute or Administrative Rule relating to Long Term Care facilities, e.g. nursing homes, memory care facilities, foster homes.
    - The main issue in the court hearing was, in my opinion, a lack of knowledge of Alzheimer's Disease by the Ombudsmen and Oregon Health Services.
      - Their view is from a legal and statutory perspective, so an Advance Directive created seven years ago was viewed as "illegal" and no longer the valid.
  - 2) Or we have an Advance Directive specifically for persons formally diagnosed with dementia or Alzheimer's Disease
- Either way, the statute would allow for the person's wishes for end of life be accepted even though 7 to 10 years have passed since the declaration

Note: The group End of Life Washington, or EOLWA, which assists people using the state's 2009 Death with Dignity Act, recently posted new ["Instructions for Oral Feeding and Drinking"](#) on its website. (3)

(3) <https://khn.org/news/new-instructions-could-let-dementia-patients-refuse-spoon-feeding/>

# Nora's Passing Thoughts

- Nora passed, October 11, 2017 of the full effects of Alzheimer's Disease.
  - She became unable to swallow, yet they still brought her food and tried to spoon feed her.
  - The doctor finally gave an order to not feed her on October 9<sup>th</sup>, one day before she began the final phase of dying
  - Hospice would not provide sufficient morphine, in my opinion, to ease her discomfort and anxiety over actually dying in the last two to three days.
    - They indicated they wanted to be careful of the side-effects or addiction issues.
  - Nora began very labored breathing around 11AM Tuesday, October 10 which continued for 14 hours until her death at 1:30AM Wednesday, morning.
- The reason for the timid response to her dying by the caregivers, hospice and doctor suggested by a social worker of Hospice was do to the heightened interest in Nora by the Ombudsman organization of the state because of the lawsuit; and the restrictions by the state on the admissions of Fern Gardens.
  - None wanted to be challenged by the Ombudsman nor by the state; hence, Nora did not have a peaceful death.
  - Interesting "coincidence" is that shortly after Nora's death, the state lifted the restrictions on admissions at Fern Gardens.

# History

- In July, 2016 I went to court to have Fern Gardens, a memory care facility, stop spoon feeding Nora Harris, my wife, in accordance to her Advance Directive. <sup>(1)</sup>
  - Nora's current state (and at the time of the hearing) was/is:
    - Does not know any friends or family members. She neither remembers them, nor does she understand her current circumstances.
    - Can not communicate in meaningful language or gestures;
    - She does not know how to eat, use a utensil, or when to eat or drink; everything must be done by another person.
    - She weighs plus or minus 95 lbs and is fed by the staff at meals.
- I lost the hearing with the judge indicating that Oregon Administrative rules (based on statute law) over-rode the advance directive.
  - The judge also indicated that she did not doubt that Nora would just hate the position she was in.
  - Nora's daughter testified that this was absolutely what Nora wanted and that "she did not want to be treated like a baby."
  - Nora's court appointed attorney talked with her friends, who testified in the hearing, and reiterated that she did not want spoon feeding. Still, he testified that **Nora changed her mind**, because she accepted food when presented to her mouth.
  - The ombudsmen law/rules state that Nora could only refuse food by turning her head, spitting it out or not open her mouth when a spoon was presented.
- I thought this was not right, to have state law overrule an Advance Directive.
  - I talked with an attorney who specialized in appeals and he told me that I had a good case as it was based on law and not a dispute over facts.
  - He also informed me that the appeal would take about 10,000 dollars and 18 to 36 months; if Nora passed during this appeal, it would stop immediately.
  - I was also informed that precedent is only created from an appeal and not from the local ruling.
  - I choose not to appeal as I did not think that Nora would live beyond 18 to 36 months.

<sup>(1)</sup> The write up of the court hearing by Medford Tribune, dated 9/17/2016, is a good recap of the proceedings. I have attached to the end of this ppt.

# History

- The ruling by the judge did the following:
  - Condemned Nora to experience the full gamut of Alzheimer's disease to the bitter end.
    - There is "no exit" for Nora, even though her Advance Directive gave her one, we thought.
    - The ending could be pneumonia from food going into her lungs, a broken hip from a fall, or an inability to swallow (ironically), etc..
- Because I had a well paying job, I was and am paying out of pocket the expenses for her care at Fern Gardens.
  - The rate is 6,000 dollars a month or 72,000 per year.
    - \$4700 for Fern Gardens, \$200 for doctor coverage, \$250 for medicines and materials (diapers), and \$ 50 miscellaneous; and
    - Nora being under 65 years of age, does not qualify for Medicare, so I have to pay for private health insurance for her which is about \$800 a month.
  - So since July of 2016, I have paid 60,000 dollars cash from my retirement assets to continue her care and
  - Over the course of these four years (2013-2017) I have paid about 288,000 dollars cash.
  - My assets will be depleted within the next 12 to 18 months to the point where I would qualify for Medicaid assistance in Nora's care under the *Preservation of Spousal Assets*, statutes.
    - However with the new health care initiative from the Republican House, Medicaid may not be available in the near future.



# Background

- Nora was diagnosed in July of 2009 with early onset Alzheimer's Disease at the age of 56.
  - Her Advance Directive which was documented and signed in September, 2009.
  - We moved from California to Ashland in July of 2011 because of Oregon's compassionate assisted suicide law and more affordable quality memory care facilities.
- I placed her in Fern Gardens in January of 2013.
  - She entered Fern Gardens at 160 plus pounds;
  - In January of 2016 she weighed 100 pounds, losing about 20 lbs in the previous two months.
  - She entered Hospice in January of 2016, and continued to lose weight to about 90 pounds and then she started to gain weight again.
  - Hospice was discontinued and I found out that Fern Gardens was spoon feeding her, because she could not understand or mechanically feed herself.
    - She had been eating finger food.
    - An Ombudsman intervened and told Fern Gardens to serve her the same food as everyone else, e.g. meat and potatoes.
    - The Ombudsman indicated that she was enforcing Oregon's Administrative rules regarding nursing homes, memory care facilities, etc..
      - OAR stated that she had to be offered three nutritious meals a day and if not able to eat, the facility must provide assistance, i.e. spoon feed her.
  - In July of 2016, I went to court. I lost.

# Who Am I?

- I am William Harris, 76 years old, who just retired on December 31, 2016 from Wells Fargo Bank.
  - I worked for them for 25 years.
  - I had planned to retire at age 67; however with Nora's diagnosis of Alzheimer's and knowing that I would have to pay out of pocket for her care, I worked an additional 8 years so that I would have the resources to pay for her care.
  - Knowing what she wanted as per her Advance Directive and the usual progression of the disease, I hoped that working until 75 would be sufficient.
  - I graduated from the University of Oregon with a Bachelor's (1964) and a Master's (1965) degree in Political Science, but through a circuitous route wound up in Information Technology in the financial industry.
  - I was facilitating 3 Alzheimer's Disease Support groups for care-givers under the Alzheimer's Association.
    - There are two groups at the Medford Senior Center and one at Rogue Valley Manor.